September 17, 2010 – submitted via <u>www.regulations.gov</u>

The Honorable Kathleen Sebelius, Secretary U.S. Department of Health and Human Services Hubert H. Humphrey Building 200 Independence Avenue, SW Washington, DC 20201

RE: File Code OCIIO-9992-IFC

Dear Secretary Sebelius:

On behalf of *Family Voices*, *Inc.*, I would like to submit the following comments on the Interim Final Rules pertaining to coverage of preventive health services under Section 2713 of the Patient Protection and Affordable Care Act (ACA).

Family Voices is a national nonprofit organization of families whose children have special health care needs, such as disabilities or chronic illnesses, and the professionals who serve them. The organization's mission is to achieve family-centered care for all children and youth with special health care needs and/or disabilities (CYSHCN).

Family Voices is also concerned with prevention of conditions that might cause children to become disabled or suffer chronic health conditions, and with prevention of complications or aggravation of such conditions. Accordingly, we are very pleased that Section 2713 of the ACA, and the accompanying interim final regulations, will afford children the evidence-informed preventive care and screening provided for in the comprehensive guidelines supported by the Health Resources and Services Administration (HRSA), also known as "Bright Futures."

In general, we commend the Department on the interim final rules, but have a few suggestions for possible improvement, as detailed below and in the letter that was co-signed by *Family Voices*, the American Academy of Pediatrics, and other national organizations.

First, as outlined in that letter, we recommend: that you require that Section 2713 be applied to Medicaid managed care programs; that health care providers not be required to absorb costs associated with Section 2713; and that grandfathered plans be required to provide full access to preventive care.

In addition, we have several other suggestions, as outlined below:

Billing practices should be monitored. We are concerned about the provision in the interim final regulations which permits the imposition of cost-sharing if an office visit is billed separately from the provision of the preventive services rendered during that visit, even if preventive care was the primary purpose of the office visit. It seems that this provision would encourage the practice of separate billing for office visits. We recommend that the Department reconsider this provision, or monitor its application, to ensure that it does not effectively abrogate the underlying principle that there should be no cost-sharing for preventive services.

Insurers should be required to provide information about preventive services to their customers. The final rule should require that insurers be obligated to notify their customers, at least annually, about which services are covered at no charge (or have ceased to be covered at no charge), the ages at which well-child visits should be scheduled, and the recommendations for other preventive services (e.g., prenatal care, adult vaccines, etc.). If a plan loses its grandfather status, and therefore must start to cover preventive services at no charge, they should be obliged to notify their customers of that fact within a reasonable period of time. The final rule should also include a mechanism to ensure that providers, including specialists, are informed of any changes to the recommended set of preventive services.

Care coordination and provider-patient communication should be reimbursed. We recommend that the final rule ensure that providers are duly compensated for the preventive care they render, including care coordination and the communication with patients/families that is integral to that care. Adequate reimbursement is needed to encourage providers to spend time communicating with parents and other caretakers of children. Communication with those who care for children is critical to their overall health, particularly for CYSHCN, whose complex conditions may require extensive care provided by family members. Adequate time is needed so that the family can communicate information and concerns to the provider, and so that the provider can communicate information to the family about how to care for the child properly. Such provider-patient communication is important in preventing complications or secondary conditions, and therefore should be encouraged by sufficient reimbursement, as well as by the professional standards guiding patient care.

Specialists should be reimbursed when they deliver preventive health services. Children with chronic or complex medical conditions may visit their medical specialists and subspecialists so often that they do not see their primary care practitioner for routine well-child visits. Instead, they may receive immunizations and other preventive services from their specialists. The final rules should clarify that these practitioners, not just designated primary care providers, should be reimbursed for preventive services they render, and that the same cost-sharing rules apply regardless of who provides the preventive services.

Preventive services should be covered regardless of when they are provided. For medical reasons, children and youth with special health care needs may not be able to receive preventive care (e.g., immunizations or developmental screenings) according to recommended schedules. The final rules should clarify that the covered preventive health services must be reimbursed, and that there should be no cost-sharing for the patient, even if those services are provided outside the time frames recommended for healthy children.

Treatment for conditions identified through screenings must be covered in the essential benefits package. It will be of little benefit to identify a problem through a health screening or other preventive service if treatment for such a condition is not covered. Therefore, we recommend that the "essential benefits package," to be defined pursuant to the ACA, include all medically necessary treatment and ancillary services to address conditions identified through the recommended preventive services. For example, covered services should include vision and

other technological aids; physical, speech, occupational and behavioral therapies; and case-management for chronic conditions such as asthma.

Families and pediatric specialists should be represented on bodies that develop guidelines for pediatric preventive services. It is essential that any boards, panels, or other bodies charged with developing or updating the covered preventive services for children (and the essential benefits package) include family members (i.e., parents/guardians), including families of CYSHCN. We recommend that actual family members, as well as organizations representing health consumers and families, be included. In addition, such bodies should include pediatric specialists and subspecialists who have expertise in caring for children with complex and/or chronic health problems and children with developmental or behavioral problems. Without such representation, recommendations may fail to take into account the circumstances of children and youth with special health care needs.

Health information technology should be used to encourage care coordination and the timely delivery of preventive services. Children with complex medical conditions often see multiple health care providers, so preventive health services sometimes "fall between the cracks." Electronic medical records could help to facilitate the care coordination critical in helping to ensure positive outcomes for children and youth with special health care needs. Such technology should include prompts for providers on the provision of preventive health services.

Thank you for your attention to our comments. If you have any questions, please feel free to contact Janis Guerney at <u>jguerney@familyvoices.org</u> or 202-546-0558.

Sincerely,

Sophie Arao-Nguyen, Ph.D.

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Executive Director